

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Models of service delivery for people with learning disabilities and behaviour that challenges

Topic

The Department of Health in England and the Department for Education have asked NICE to develop a social care guideline on models of service delivery for children, young people and adults with learning disabilities and behaviour that challenges.

Who the guideline is for

- Providers of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges.
- Health and social care practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers.

It will also be relevant to:

- Children, young people and adults with learning disabilities and behaviour that challenges and their families and carers, including people who purchase their own care.
- Commissioners of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges
- Practitioners working with children, young people and adults with learning disabilities and behaviour that challenges in related services, including housing, employment, education and housing.

- 28 • Providers of related services, including housing, education, employment
29 and criminal justice services

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31 NICE guidelines cover health and care in England. Decisions on how they
32 apply in other UK countries are made by ministers in the [Welsh Government](#),
33 [Scottish Government](#), and [Northern Ireland Executive](#).

34 ***Equality considerations***

35 NICE has carried out [an equality impact assessment](#) during scoping. The
36 assessment:

- 37 • lists equality issues identified, and how they have been addressed
38 • explains why any groups are excluded from the scope, if this was done.

39 **1 What the guideline is about**

40 ***1.1 Who is the focus?***

41 **Groups that will be covered**

42 Children, young people and adults with mild, moderate, severe or profound
43 learning disabilities¹ and behaviour that challenges, and their families and
44 carers.

45 **Groups that will not be covered**

- 46 • Adults with learning disabilities whose behaviour that challenges may be
47 attributed to dementia.

¹ The NICE clinical guideline on challenging behaviour and learning disabilities specifies that: 'A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability.' This definition of challenging behaviour and learning disabilities will also be used in this guideline.

48 **1.2 Settings**

49 **Settings that will be covered**

- 50 • The guideline will cover models of service delivery for children, young
51 people and adults, provided or commissioned by health or social care, in
52 whatever care setting the person receives care and support, including:

53

54 **Inpatient settings**

- 55 – Specialist learning disability assessment and treatment units
- 56 – Adult mental health and learning disability inpatient settings (including
57 secure settings).
- 58 – Older people’s mental health and learning disability inpatient settings
- 59 – Children’s mental health and learning disability inpatient settings
60 (including tier 4 CAMHS and secure settings)

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62 **Care home settings**

- 63 – All residential and nursing care homes.
- 64 – Care homes for children (including secure children’s homes)

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66 **Community settings**

- 67 – People’s own homes and other housing, including temporary
68 accommodation.
- 69 – Foster care
- 70 – Extra care housing (such as warden-supported, sheltered or specialist
71 accommodation).
- 72 – Shared Lives Scheme (formerly Adult Placement Scheme) living
73 arrangements.
- 74 – Supported living.
- 75 – Day care settings.
- 76 – Residential schools.

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79 **1.3 Activities, services or aspects of care**

80 **Key areas that will be covered**

81 We have produced a guideline on [prevention and interventions for people with](#)
82 [learning disabilities whose behaviour challenges](#). This new service guideline
83 will focus on how services are organised and configured to deliver these
84 interventions effectively. The guideline will cover:

- 85 1 Models of service delivery
- 86 2 Service capacity
- 87 3 Location of services
- 88 4 Types of service provision (including alternatives to inpatient provision)
- 89 5 Timely access to services
- 90 6 Timely access to staff with a given competency or skill
- 91 7 Integration of health and social care services for people with learning
92 disabilities and behaviour that challenges
- 93 8 Joint working with related services, including:
 - 94 - Housing
 - 95 - Education
 - 96 - Employment
 - 97 - Criminal justice services
- 98 9 Safeguarding
- 99 10 Risk management

100 **Areas that will not be covered**

- 101 1 Treatment, therapy, prevention and management of behaviour that
102 challenges in people with learning disabilities. This is covered in NICE's
103 guideline on [prevention and interventions for people with learning](#)
104 [disabilities whose behaviour challenges](#).

105 **1.4 Economic aspects**

106 We will take economic aspects into account when making recommendations.
107 We will develop an economic plan that states for each review question (or key
108 area in the scope) whether economic considerations are relevant, and if so

109 whether this is an area that should be prioritised for economic modelling and
110 analysis. We will review the economic evidence and carry out economic
111 analyses, using a public sector perspective, as appropriate.

112 **1.5 Key issues and questions**

113 While writing this scope we have drafted the review questions listed below.
114 Please note these are only example questions. A full list of review questions
115 covering all of the key areas and issues in the scope will be agreed by the
116 Guideline Committee at the start of guideline development.

117 1 Models of service delivery

118 - What models of service delivery are effective and cost-effective for
119 people with learning disabilities and behaviour that challenges?

120 2 Service capacity

121 - What is the appropriate inpatient bed capacity to facilitate service
122 user flow for people with learning disabilities and behaviour that
123 challenges?

124 3 Types of service provision

125 - What types of community-based provision are effective and cost-
126 effective for people with learning disabilities and behaviour that
127 challenges?

128 4 Integration of services

129 – What mechanisms enable effective joined-up working between
130 service providers supporting people with learning disabilities and
131 behaviour that challenges and their families and carers?

132 5 Timely access to service

133 - What models of delivery facilitate timely access to services for people
134 with learning disabilities and behaviour that challenges?

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137 **1.6 Main outcomes**

138 The main outcomes that will be considered when searching for and assessing
139 the evidence are:

140 1 Person-focused outcomes:

- 141 – Service user and carer satisfaction
- 142 – Mental wellbeing and psychological health outcomes.
- 143 – Health and social care related quality of life.
- 144 – Involvement of people using services, their families and carers in the
- 145 planning, delivery and monitoring of services.
- 146 – Inclusion in community life.
- 147 – Capability to achieve desired, person-centred outcomes as listed in
- 148 the 9 areas of wellbeing set out in the [Care Act 2014](#).
- 149 – Carer stress and resilience.
- 150 – Continuity of care.

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152 2 Service-focused outcomes

- 153 – Use of seclusion.
- 154 – Use of manual restraint.
- 155 – Use of psychoactive medication.
- 156 – Use of inpatient placements (including out-of-area placements).
- 157 – Extent to which general and complex physical and mental health
- 158 needs are met.
- 159 – Timely discharge: length of hospital stay; delayed transfers of care
- 160 from hospital.
- 161 – Availability, access and uptake of local services.
- 162 – Use of health and social care services (primary and secondary;
- 163 inpatient, residential and community).
- 164 – Level and type of support from care workers and carers.

165 **2 Links with other NICE guidance, NICE quality** 166 **standards and NICE Pathways**

167 **2.1 NICE guidance**

- 168 • [Challenging behaviour and learning disabilities: prevention and](#)
169 [interventions for people with learning disabilities whose behaviour](#)
170 [challenges](#) (2015) NICE guideline NG11.
- 171 • [Violence and aggression: short-term management in mental health, health](#)
172 [and community settings](#) (2015) NICE guidelines NG10.
- 173 • [Autism: the management and support of children and young people on the](#)
174 [autism spectrum](#) (2013) NICE guideline CG170.

175 **NICE guidance about the experience of people using NHS services**

176 NICE has produced the following guidance on the experience of people using
177 the NHS. This guideline will not include additional recommendations on these
178 topics unless there are specific issues related to people with learning
179 disabilities and behaviour that challenges:

- 180 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138.
- 181 • [Service user experience in adult mental health](#) (2011) NICE guideline
182 CG136.

183 **NICE guidance in development that is closely related to this guideline**

184 NICE is currently developing the following guidance that is closely related to
185 this guideline:

- 186 • [Transitions between inpatient mental health settings and community and](#)
187 [care home settings](#). NICE guideline. Publication expected August 2016.
- 188 • [Transitions between inpatient hospital settings and community or care](#)
189 [home settings for adults with social care needs](#). NICE guideline. Publication
190 expected November 2015.
- 191 • [Transitions from children to adult services](#) NICE guideline. Publication
192 expected February 2016.

- 193 • [Care and support of older people with learning disabilities](#) NICE guideline.
194 Publication expected October 2017.
- 195 • [Mental health problems in people with learning disabilities](#). NICE guideline.
196 Publication expected September 2016.

197 **2.2 NICE quality standards**

198 NICE quality standards that may use this guideline as an evidence source
199 when they are being developed or updated:

- 200 • [Autism](#) (2013) NICE quality standard QS51.
201 • [Supporting people to live well with dementia](#) (2013) NICE quality standard
202 QS30.

203 **2.3 NICE Pathways**

204 When this guideline is published, the recommendations will be added to [NICE](#)
205 [Pathways](#). NICE Pathways bring together all related NICE guidance and
206 associated products on a topic in an interactive topic-based flow chart.

207 **3 Context**

208 **Key facts and figures**

209 Approximately 1 million people in England have a learning disability and of
210 these people it is estimated that 10–17% behave in a way that challenges
211 ([Predictors, costs and characteristics of out of area placement for people with](#)
212 [intellectual disability and challenging behaviour](#), Allen et al. 2007). Rates are
213 higher in teenagers and people in their early 20s.

214 The most commonly used definition of behaviour that challenges is
215 'behaviour of such an intensity, frequency or duration that the physical safety
216 of the person or others is likely to be placed in serious jeopardy, or behaviour
217 which is likely to seriously limit or delay access to and use of ordinary
218 community facilities' (Emerson et al 1987).

219 The Government strategy, [Valuing People Now](#) identified that often these
220 behaviours are the only way that people have of communicating that their

221 needs are not being met. The report notes that it is essential to address these
222 behaviours because 'ignoring them may put lives at risk'.

223 **3.1 Current practice**

224 **Moving from hospital to community-based support**

225 The exposure of widespread abuse at Winterbourne View in 2011 led to a full
226 enquiry by the Government. Following that enquiry, a number of national
227 organisations signed up to the Winterbourne View Concordat, and as part of
228 that NHS England agreed to 'review all current hospital placements and
229 support everyone inappropriately placed in hospital to move to community-
230 based support as quickly as possible and no later than 1 June 2014'. Progress
231 has been slow and subsequent reporting showed that only 260 out of 2577
232 people in hospital with learning disabilities and challenging behaviour had a
233 planned transfer date. Only 172 transfers happened before the 1 June 2014
234 deadline.

235 Not everyone in hospital is inappropriately placed: and some may be under
236 treatment orders from the ministry of justice. However, there are still a large
237 number of people who do not have a planned transfer date from the date of
238 admission.

239 **Transforming care – next steps**

240 A report by the Transforming Care and Commissioning Steering Group
241 chaired by Stephen Bubb (2014) stated that clinicians 'are being asked to
242 keep people in the community or discharge to the community when many will
243 worry that the community-based support on offer is insufficient, or not there at
244 all'.

245 **Out-of-area placements**

246 The Department of Health ([Winterbourne View: good practice examples](#))
247 notes that sending people to placements out of area can cause 'real harm to
248 individuals by weakening their relationships with family and friends and taking
249 them away from familiar places and community. It can damage continuity of
250 care. It can also mean putting people into settings that they find stressful or

251 frightening. This can damage mental health or increase the likelihood of
252 challenging behaviour arising'.

253 Feedback from 13 learning disabilities commissioners found that young men
254 with learning disabilities, challenging behaviour and/or autism continue to
255 receive very high cost residential support, often in out-of-area residential care.
256 There is limited evidence of plans to redirect resources to more local service
257 developments. According to the report 54% of people had care plans but only
258 3% has been given a discharge date. Almost three quarters (71%) of
259 placements were out of area (McGill and Poynter 2012).

260 **Budget pressures**

261 The National Audit Office (2015) states that around 'half of inpatients are
262 funded directly by NHS England. There can be substantial extra costs to local
263 health and care commissioners to meet discharged patients' community care
264 needs when their hospital care was previously funded by NHS England'. The
265 report highlights that budget pressures have led clinical commissioning groups
266 and local authorities to cut resources for mental health hospitals and
267 community based learning disability teams, including staffing. Some 'specialist
268 learning disabilities teams in the community have been run down, which has
269 contributed to delays in introducing appropriate care packages. This has also
270 increased the risk of hospital admissions, and readmissions, and the
271 pressures on hospital resources'.

272 The implication of this is that reductions in community services are causing
273 some people to remain in expensive hospital placements longer than is
274 necessary, which is both bad for the person and a poor use of resources.

275 **3.2 Policy, legislation, regulation and commissioning**

276 **Policy**

277 The 2000 white paper [Valuing People: A New Strategy for Learning Disability](#)
278 [for the 21st Century](#) signalled a new approach to the delivery of care for
279 people with learning disabilities and their families. [Valuing People Now](#)
280 (Department of Health) up-dated the original strategy and set out a three year

281 strategy for implementing the change in approach of delivering services set
282 out in it.

283 The reports from [Learning Disabilities Good Practice Project](#) (Department of
284 Health), [Improving health and care: the role of the outcomes frameworks](#)
285 (Department of Health) [Valuing People Now: Summary Report March 2009 to](#)
286 [September 2010 \(Good Practice Examples\)](#) list several examples of local
287 practice innovations.

288 This guideline will consider good practice examples as well as draw from the
289 experience and knowledge of the guideline committee to review the
290 effectiveness of different configurations of services and service models. The
291 guidelines will also include the views and experiences of good practice from
292 people using services, their families and carers and practitioners.

293 **Legislation**

294 Listed below are some of the key pieces of legislation and statutory guidance
295 for people with learning disabilities and behaviour that challenges. This is not
296 intended to be an exhaustive list; rather it provides additional context for the
297 guideline work.

- 298 • [Care Act 2014](#) setting out the duties and powers of local authorities to
299 provide care and support to people using services and their carers.
- 300 • [Children Act 1989](#).
- 301 • [Children and Families Act 2014](#).
- 302 • [Care Standards Act 2000](#).
- 303 • [Carers and Disabled Children Act 2000](#)
- 304 • [Mental Health Act 1983 Part II: Compulsory admission to hospital and](#)
305 [guardianship](#).
- 306 • [Mental Health Act 1983 Part III: Patients concerned in criminal proceedings](#)
307 [or under sentence](#).
- 308 • [The Mental Capacity Act 2005](#).

309 **Commissioning**

310 The commissioning of services for people with learning disabilities and
311 challenging behaviour involves local authorities, CCGs and NHS England and
312 can be fragmented. Provision is split between state-run and independent
313 (mostly for profit). Often there is a lack of incentive to discharge and transfer
314 people out of hospital or residential provision.

315 The [Services for people with learning disability and challenging behaviour or](#)
316 [mental health needs](#) (Department of Health, 2007) report found that
317 commissioning was 'too reactive', and there is evidence that this still applies.
318 It was noted that decisions to buy services are often made 'on the basis of
319 lowest cost in the short-term, without considering the long-term effects when
320 things go wrong'. Often, local services are still fragmented, disconnected and
321 poorly designed and there is no consistent model for challenging behaviour
322 services applied across the country.

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324 **4 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 15 July to 02 September 2015.

The guideline is expected to be published in September 2017.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.

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